

Expectations About the Effectiveness of Radiation Therapy Among Patients With Incurable Lung Cancer

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ABSTRACT

Purpose

Although radiation therapy (RT) can palliate symptoms and may prolong life, it is not curative for patients with metastatic lung cancer. We investigated patient expectations about the goals of RT for incurable lung cancers.

Patients and Methods

The Cancer Care Outcomes Research and Surveillance Consortium enrolled a population- and health system-based cohort of patients diagnosed with lung cancer from 2003 to 2005. We identified patients with stage wet IIIB or IV lung cancer who received RT and answered questions on their expectations about RT. We assessed patient expectations about the goals of RT and identified factors associated with inaccurate beliefs about cure.

Results

In all, 384 patients completed surveys on their expectations about RT. Seventy-eight percent of patients believed that RT was very or somewhat likely to help them live longer, and 67% believed that RT was very or somewhat likely to help them with problems related to their cancer. However, 64% did not understand that RT was not at all likely to cure them. Older patients and nonwhites were more likely to have inaccurate beliefs, and patients whose surveys were completed by surrogates were less likely to have inaccurate beliefs. Ninety-two percent of patients with inaccurate beliefs about cure from RT also had inaccurate beliefs about chemotherapy.

Conclusion

Although patients receiving RT for incurable lung cancer believe it will help them, most do not understand that it is not at all likely to cure their disease. This indicates a need to improve communication regarding the goals and limitations of palliative RT.

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INTRODUCTION

Lung cancer is the leading cause of cancer death in both men and women. About half of patients have metastatic disease at diagnosis, with most surviving less than 1 year, even with intensive therapies.^{1,2} Therefore, the clinical focus in these patients is not only to extend life but also to manage symptoms and maintain quality of life. Radiation therapy (RT) can be used to palliate symptoms from intrathoracic disease as well as symptomatic metastases, and more than 50% of patients with stage IV lung cancer receive RT at some point in their disease course.³ Although palliative RT is effective at relieving symptoms, it is not curative, and treatments typically require daily visits to specialized treatment facilities, which can impose significant time and financial burdens on patients and their families.

There is a wide range in the number of palliative RT treatments that may be delivered, and prior

work suggests that many patients may receive lengthier courses than necessary.⁴⁻⁸ Although this may simply reflect provider and patient preferences or differences in clinical scenarios, prior studies suggest that providers not only may be overly optimistic about patient prognosis but may also have difficulty communicating prognosis to patients with terminal cancer.⁹⁻¹² In addition, considerable evidence suggests that patients with cancer may hold unrealistic beliefs about prognosis and the potential efficacy of treatment.¹²⁻¹⁵ By using data from the Cancer Care Outcomes Research and Surveillance Consortium (CanCORS), our group recently found that patients with metastatic lung and colon cancer frequently did not understand that chemotherapy was not curative.¹⁶ Because RT is frequently used in the palliative care of patients with lung cancer, it is important for patients to understand both the goals and limitations of RT in order to make the best decisions about the care they elect to receive near the end of life. We

therefore sought to characterize patient expectations about the goals of RT in a population- and health system–based cohort of patients with incurable lung cancer and to compare patient expectations about chemotherapy versus radiation.

PATIENTS AND METHODS

Sources of Data

The CanCORS study prospectively enrolled patients age 21 years or older who were diagnosed with lung cancer in Northern California, Los Angeles County, North Carolina, Iowa, and Alabama or who received care in one of 10 Veterans Administration sites or one of five large health maintenance organizations from 2003 to 2005. Patients were identified within 3 months of diagnosis from population-based cancer registries at geographic sites and from pathology and cytology records at organizational sites. The study was approved by human subjects committees at all participating institutions, and all patients gave written informed consent to participate.^{17,18} The characteristics of the CanCORS population have been shown to correspond well to the Surveillance, Epidemiology, and End Results (SEER) population, although the age distribution is slightly younger.¹⁹

Patients completed a telephone survey administered by trained interviewers about multiple facets of their experience with cancer care 4 to 7 months after diagnosis. For those unable to participate in the full survey, a brief version was given, or surrogates were surveyed when patients were too ill or deceased. Medical records were abstracted from all providers involved in the patients' cancer care from 3 months before through 15 months after diagnosis.

Study Cohort

We identified patients who presented with incurable lung cancer, defined as stage IV or IIIB with malignant effusion at diagnosis (American Joint Committee on Cancer [AJCC] Cancer Staging Handbook, 6th edition).¹ The study cohort included patients who reported that they had received or were scheduled to have RT and who completed survey items on their expectations about RT. Since these items were not included on surveys given to surrogates of deceased patients or a version of the brief patient survey used at some of the data collection sites, patients who had only these data were not eligible. Figure 1 summarizes the construction of the study cohort.

Expectations About RT

Patients were asked about their expectations about the goals of RT by using an item adapted from the Los Angeles Women's Health Study.²⁰ "After talking with your doctors about radiation therapy, how likely did you think it was that radiation would...help you live longer? cure your lung cancer? help you with problems you were having because of your lung cancer?" Response options included "very likely," "somewhat likely," "a little likely," "not at all likely," "don't know," or refused.

Covariates

Sociodemographic characteristics, including sex, marital status, race, and insurance, were obtained from the survey. For patients with missing information in the survey, data from the medical record abstraction were used when available. All variables were grouped into mutually exclusive categories as depicted in Table 1. Patients with any Medicaid coverage were classified in the Medicaid group.

Physical functioning was classified as "good" if the patient reported no problems with mobility, no problems with self-care, and no or some problems performing usual activities and classified as "poor" otherwise, on the basis of three items from the EQ-5D, a standardized instrument for measuring health-related quality of life.²¹ Patients were also categorized by the CanCORS Primary Data Collection and Research (PDCR) site where they enrolled.

Statistical Analysis

Patient expectations about the goals of RT were summarized descriptively. Expectations about the likelihood of cure from palliative RT were

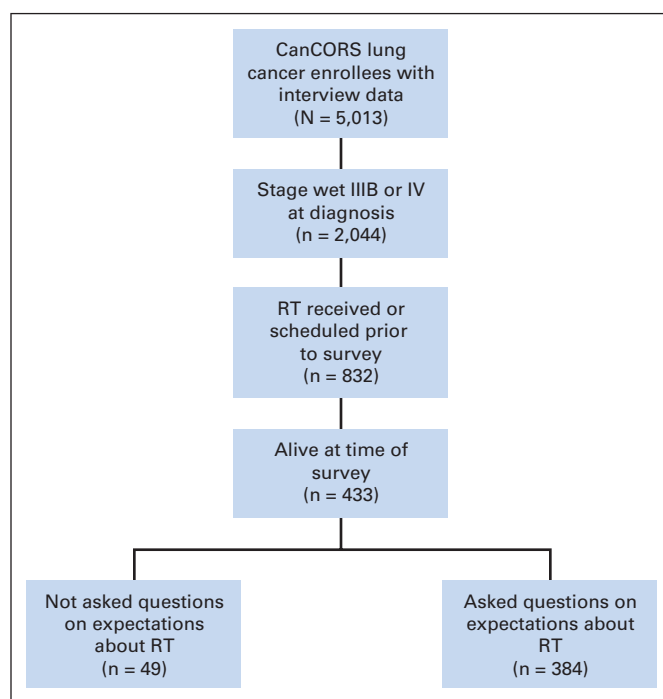


Fig 1. Study cohort. CanCORS, Cancer Care Outcomes Research and Surveillance Consortium; RT, radiation therapy.

further dichotomized as "accurate" versus "inaccurate." Responses of "very likely," "somewhat likely," and "a little likely" to cure lung cancer, as well as "don't know" or refused were considered inaccurate, whereas a response of "not at all likely" to cure lung cancer was considered accurate. Sensitivity analyses were performed with patient responses treated as a four-level ordinal variable, excluding patients with responses of "don't know" or refused since those responses do not follow a natural order.

Univariable logistic regression was used to assess associations between patient and provider variables and inaccurate beliefs about whether palliative RT was likely to be curative. In addition to demographic variables listed in Table 1, we assessed the effect of physician-patient and patient-family decision-making style as well as physician rating on inaccurate beliefs of cure. None of these were significantly associated with expectations of cure so were not included in the multivariable model. Significant variables as well as other a priori variables of interest were included in a multivariable logistic regression model to identify variables independently associated with use of RT. Item nonresponse was less than 2% for items that were included on all versions of the survey. The item on income was not included on the brief interview, resulting in missing data for 13% of responses. Logistic regression analysis was conducted on multiply imputed data to adjust for the item nonresponse of CanCORS.^{22,23} Imputed values were not used for the outcome variables. Twenty-three patients were excluded from the regression analyses because they were not given imputed values for certain items because of structured missingness.

Prior work has shown that many patients with advanced cancer in CanCORS have inaccurate beliefs about cure from chemotherapy,¹⁶ so we also evaluated the association between inaccurate beliefs about RT and inaccurate beliefs about chemotherapy among patients with incurable lung cancer who completed survey items about both treatment modalities.

P values were two-sided, and values less than .05 were considered statistically significant. Statistical analyses were conducted with CanCORS core data (version 1.15) and patient survey data (version 1.12) by using SAS version 9.2 (SAS Institute, Cary NC) and STATA version 11.1 (STATA, College Station, TX).

Table 1. Patient Characteristics

Characteristic	No.	%
No. of patients	384	100
Stage (AJCC 6th edition)		
Wet IIIB	39	10
IV	345	90
Histology		
Non-small cell	314	82
Small cell	70	18
Age at diagnosis, years		
21-54	84	22
55-64	117	31
65-74	111	29
75+	71	19
Sex		
Male	230	60
Female	154	40
Marital status		
Married/living as married	246	64
Unmarried	136	35
Unknown	2	0.5
Race/ethnicity		
White	270	70
African American	53	14
Other	61	16
Education		
Less than high school	80	21
High-school graduate	162	42
Some college or more	141	37
Unknown	1	0.3
Income, \$		
< 20,000	115	30
20,000-39,999	109	28
40,000-59,999	55	14
> 60,000	55	14
Unknown	50	13
PDCR site		
Cancer Research Network	55	14
Northern California	66	17
Alabama	71	18
Los Angeles	69	18
Iowa	77	20
Veterans Administration	46	12
Baseline interview type		
Full	267	70
Brief	17	4
Surrogate (patient too sick)	100	26
Good physical function (EQ-5D good)		
No	139	36
Yes	125	33
Unknown	120	31

Abbreviations: AJCC, American Joint Committee on Cancer; PDCR, Primary Data Collection and Research [Cancer Care Outcomes Research and Surveillance Consortium site].

RESULTS

Of 5,013 patients with a diagnosis of lung cancer enrolled onto CanCORS with survey data, 2,044 had incurable disease at diagnosis. Of these, at the time of the survey, 832 patients (41%) had either received or had been scheduled to receive RT, and 433 were alive. Of these, 384 were asked questions about their expectations about RT. Table 1

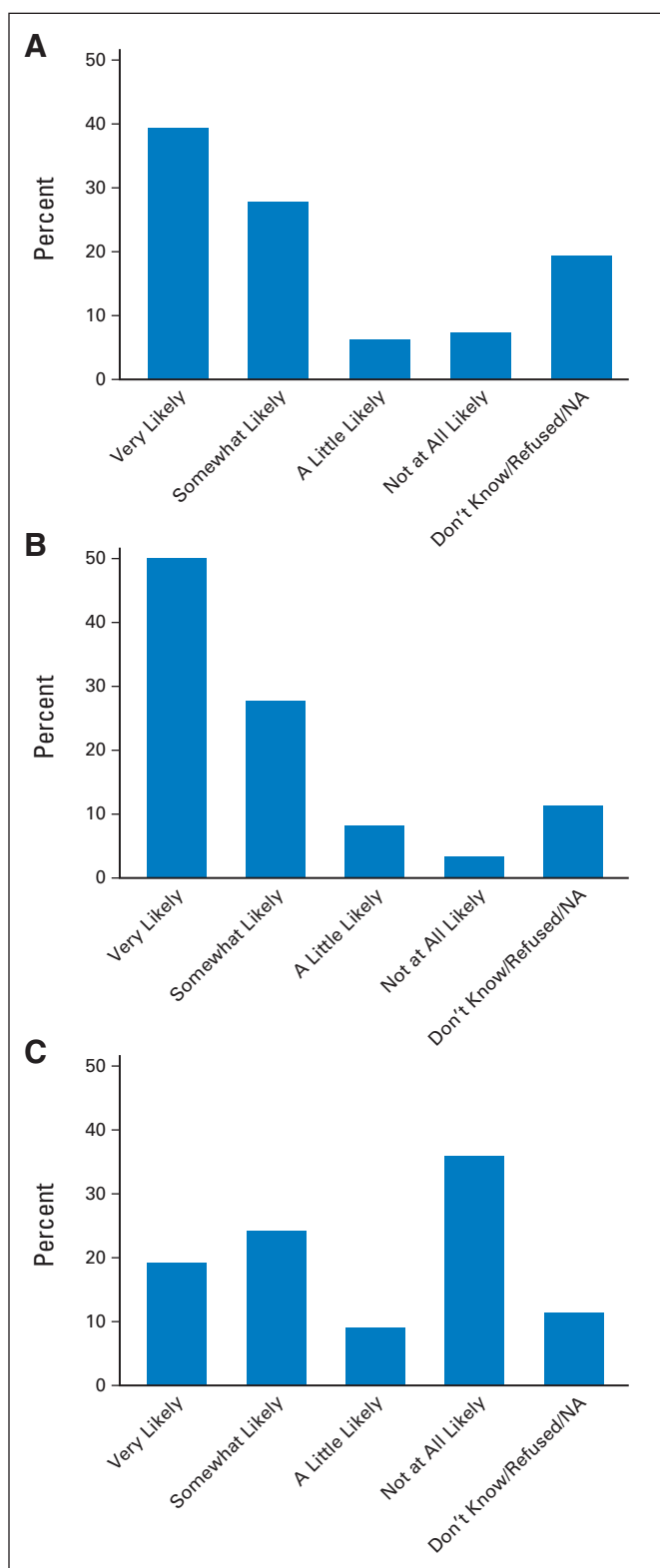


Fig 2. Patient expectations about the effectiveness of radiation therapy (RT; n = 384). (A) Radiation would help you with problems you were having because of your lung cancer? (B) Radiation would help you live longer? (C) Radiation would cure your lung cancer? NA, not applicable.

summarizes the characteristics of patients in our cohort. The median age at the time of diagnosis was 63 years, and the median survival was 11.5 months. Among our cohort, 345 (90%) had stage IV disease at diagnosis and 314 (82%) had non–small-cell histology.

Regarding expectations about the effectiveness of RT, 67% felt that RT was very or somewhat likely to help them with problems they were having because of their cancer, 78% felt that RT was very or somewhat likely to help them live longer, and 43% felt that it was very or somewhat likely to cure their cancer. Patient responses to survey items on expectations about the effectiveness of RT are shown in Figure 2. We did not observe significant differences in overall survival on the basis of patient expectations about the likelihood of RT helping them live longer or curing their cancer (data not shown).

The proportion of patients who did not accurately understand that palliative RT was “not at all likely” to cure their cancer was 64%. Table 2 shows the unadjusted and adjusted analyses of factors associated with inaccurate beliefs about cure from RT. On multivariable analysis, older patients were more likely to have inaccurate beliefs (with age younger than 55 years as the reference, odds ratio [OR] was 1.44 for ages 55 to 64 years, 1.78 for ages 65 to 74 years, and 2.45 for ages older than 74 years; overall $P = .02$) as were patients of nonwhite race (African American OR, 1.48; other non-whites OR, 3.32; overall $P = .009$), and patients whose surveys were completed by surrogates because they were too sick were less likely to have inaccurate beliefs (OR, 0.54; $P = .04$). Likelihood of inaccurate beliefs also varied by PDCR site (overall $P = .04$). To assess

Table 2. Factors Associated With Inaccurate Beliefs About Likelihood of Cure From RT (N = 361*)

Factor	% Who Did Not Respond That RT Was “Not at All Likely” to Cure Their Cancer	Unadjusted (univariable) Model			Adjusted (multivariable) Model; Includes PDCR		
		OR†	95% CI	P	OR†	95% CI	P
Age at diagnosis, years‡				.08			.02
21-54	58	Ref			Ref		
55-64	63	1.29	0.72 to 2.31		1.44	0.75 to 2.74	
65-74	65	1.58	0.86 to 2.88		1.78	0.91 to 3.46	
75+	70	1.76	0.88 to 3.52		2.45	1.13 to 5.32	
Sex				.58			.51
Male	63	Ref			Ref		
Female	66	1.13	0.73 to 1.76		1.20	0.71 to 2.03	
Marital status				.75			.70
Married/living as married	63	Ref			Ref		
Unmarried	65	1.08	0.68 to 1.69		0.89	0.50 to 1.60	
Race/ethnicity				.007			.009
White	59	Ref			Ref		
African American	75	2.06	1.05 to 4.05		1.48	0.69 to 3.15	
Other	77	2.52	1.27 to 5.00		3.32	1.52 to 7.24	
Education				.048			.15
Less than high school	76	Ref			Ref		
High-school graduate	61	0.54	0.29 to 1.00		0.67	0.33 to 1.34	
Some college or more	60	0.46	0.25 to 0.86		0.48	0.22 to 1.02	
Income, \$‡				.32			.55
< 20,000	67	Ref			Ref		
20,000-39,999	62	0.85	0.50 to 1.47		1.06	0.56 to 2.01	
40,000-59,999	64	0.87	0.46 to 1.66		1.22	0.55 to 2.70	
> 60,000	58	0.69	0.35 to 1.36		1.28	0.52 to 3.14	
PDCR site				.02			.04
Cancer Research Network	65	Ref			Ref		
Northern California	59	0.86	0.39 to 1.89		0.72	0.30 to 1.68	
Alabama	76	1.93	0.84 to 4.42		2.12	0.81 to 5.52	
Los Angeles	68	1.22	0.55 to 2.73		1.06	0.44 to 2.51	
Iowa	49	0.57	0.27 to 1.22		0.64	0.28 to 1.47	
Veterans Administration	70	1.51	0.60 to 3.81		1.66	0.59 to 4.66	
Baseline interview type				.28			.04
Full	66	Ref			Ref		
Surrogate (patient too sick)	59	0.77	0.47 to 1.24		0.54	0.30 to 0.98	
Good physical function (EQ-5D good)				.36			.44
No	63	Ref			Ref		
Yes	69	1.27	0.77 to 2.11		1.29	0.68 to 2.48	

Abbreviations: OR, odds ratio; PDCR, Primary Data Collection and Research [Cancer Care Outcomes Research and Surveillance Consortium site]; Ref, reference; RT, radiation therapy.

*Excludes 23 patients without imputed values.

†OR > 1 reflects greater likelihood of inaccurate belief.

‡P values were determined by a test for trend across the ordered categories.

Table 3. Inaccurate Beliefs About RT Versus Chemotherapy Among 285 Patients Responding to Survey Items About Both Treatment Modalities

Inaccurate Belief About Chemotherapy	Inaccurate Belief About RT		Total
	Yes	No	
Yes	167	37	204
No	15	66	81
Total	182	103	285

NOTE. Patients with inaccurate beliefs about radiation therapy (RT) were significantly more likely to also have inaccurate beliefs about chemotherapy ($P = .002$ by McNemar's test).

the robustness of our model, we also tested an alternate specification of the outcome variable by using ordinal logistic regression of the four-level response about treatment effectiveness (excluding responses of "don't know" or refused). This model specification did not substantially alter our findings.

Among 285 patients in our cohort who also completed survey items on their expectations about chemotherapy, we found that patients with inaccurate beliefs about RT were significantly more likely to also have inaccurate beliefs about chemotherapy ($P = .002$ by McNemar's test); 92% of patients with inaccurate beliefs about RT also had inaccurate beliefs about chemotherapy (Table 3).

DISCUSSION

Surveying a population- and health system-based cohort of patients with incurable lung cancer showed that a large proportion held inaccurate beliefs about the likelihood of cure from RT: 64% did not understand that RT was not at all likely to cure them. On the other hand, most patients treated with palliative RT believed that it could help them, with 67% endorsing the view that RT was very or somewhat likely to help them with problems from their cancer and 78% believing that it was very or somewhat likely to help them live longer. These results are consistent with our group's recent finding that 69% of patients receiving chemotherapy for metastatic lung cancer did not understand that it was not at all likely to cure their cancer.¹⁶

Several studies have demonstrated that physicians tend to be overly optimistic when predicting expected survival of patients with terminal cancers,^{9,24} including those referred for palliative RT.¹⁰ Others have identified challenges in communication between providers and patients referred for palliative treatment, including disclosure of prognosis, presentation of management options, assessment of understanding, and supportive remarks.^{11,12,25} In one study, hospice physicians were surveyed about their estimate of the patient's prognosis, as well as what prognosis the physician would communicate. In addition to being overly optimistic concerning their patients' prognosis, only 37% favored a frank disclosure of prognosis. Of those that favored discrepant disclosure, most favored communication of overly optimistic estimates of prognosis.²⁶

Given these challenges, it is not surprising that inaccurate patient beliefs regarding cure from cancer treatment arise. One study of patients with metastatic cancer found that one-third believed that they had local or regional disease and were being treated

for cure.¹³ Even when presented with accurate information, many patients may retain inaccurate beliefs. A pilot study in patients with advanced non-small-cell lung cancer showed that, even after presenting patients with a decision aid that improved their understanding of the goals, toxicity, and prognosis from chemotherapy, many patients retained the inaccurate belief that their cancer was curable.²⁷ Our study suggests that similar concerns may apply to RT.

Poor understanding of treatment goals and prognosis are problematic for both medical and policy reasons. Patients cannot make well-informed decisions about their end-of-life care, taking into account risks and benefits of treatment, if they hold inaccurate beliefs about the goals of care. Studies have shown that patients with advanced cancer who do not understand and overestimate their prognosis are more likely to pursue intensive therapies near the end of life.^{14,28} These therapies may reduce quality of remaining life and incur substantial costs for patients with limited life expectancy. In particular, palliative RT requires daily visits for treatment, which can be burdensome for patients and families. It is possible that patients who understand that RT is not at all likely to result in cure might choose to forgo RT or pursue shorter courses of treatment. Although randomized studies suggest that short courses of RT are equally effective in many patients with poor prognosis,²⁹ lengthier courses are more commonly given.⁸

Interventions designed to introduce patients to palliative care services earlier in the disease process have been shown to be associated with greater patient understanding of prognosis and to reduce the use of chemotherapy near the end of life.¹⁴ Although our study finds much room for improvement in patient understanding of RT, it remains to be seen whether similar interventions would be effective. Our finding that inaccurate beliefs about RT were significantly associated with inaccurate beliefs about chemotherapy indicates that the gap in understanding exists for multiple provider types and treatment modalities. Patients may lack an overall understanding of their disease process and might benefit from broader discussions that encompass more than just the risks and benefits of a particular treatment modality.

Our observation that inaccurate beliefs were associated with older age and nonwhite race, even after controlling for other factors such as education and income, suggests that generational or cultural differences may influence patients' expectations about cure and that greater efforts to improve communication with these patients may be warranted. It is not surprising that patients who required a surrogate to complete their survey because they were too sick were more likely to have accurate expectations about the likelihood of cure. This argues, however, that patients need to be better informed about their prognosis earlier in the disease process and while they can still have a meaningful impact on their course of care.

A primary strength of our study is that it surveyed a diverse population of patients with lung cancer on their expectations about treatment. Prior studies have typically included only highly selected groups of patients at single institutions. However, the population- and health system-based design also resulted in limitations in the level of detail that could be obtained. Furthermore, although the CanCORS study made an effort to recruit a representative sample of patients with lung cancer, we were not able to ascertain the expectations of patients who declined to participate in the study, were too sick to complete the survey, or were deceased by the time it was given. It is possible that patients who participated were different from those who did not, and it is possible that patients who died quickly had a different understanding of the goals of treatment. The survey was conducted following diagnosis, and therefore only patients

AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

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Provision of study materials or patients: Jane C. Weeks

Collection and assembly of data: Angel Cronin, Jane C. Weeks

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